

**External Partners Group Meeting
NCBDDD National Conference
Washington, D.C.
July 25, 2004**

EPG Brainstorming Session

The following summarizes participant discussions in three key areas at the EPG meeting. Participants split up into small groups and were asked to discuss the following areas.

- 1. Identify key policy on which the EPG should focus during the coming year.**
- 2. Identify ways that EPG could gain additional input from members and expand communication and participation.**
- 3. Brainstorm possible future activities and events for the EPG**

Policy Issues

- Translation of knowledge to community practice
 - Health disparities – access in terms of best practice
- Screening – from preconception and on (lifespan approach)
 - CDC should develop ideal and minimum screening guidelines
 - Link with HRSA, NICHD & SAMHSA
- Full funding of NCBDDD programs
 - Advocate for budget? How do we select 3 priority ideas for funding?
- Environmental toxins – bio-monitoring
 - What role does the EPG & NCBDDD have to increase knowledge, awareness, relevance and impact on conditions and disorders?
 - Advocacy around program development
 - Coordinating Health Tracking Information Initiative relationship to the EPG.
- Transition from adolescent to adulthood
 - Looking for CDC to provide support to public health departments to work with existing community health programs to coordinate efforts.
- Health promotion
 - Link with obesity programs at federal & state levels.
 - The role of genomics?
- Be watchful of pending federal/state legislation and the role the EPG can have to influence this.

Obtain Input & Expand Communications & Participation

- How to get more people involved in the EPG?

- What's in the name? Some groups do not feel represented at the table because they do not see themselves included in the name of the Center.
 - What is the purpose of the EPG? Why are we here? Will not get total buy-in to get more involved until we answer this question. Administrative Guidelines are very important and will hopefully enable members to get more involved.
 - How can we move forward?
 - What are the issues?
- EPG Hill Event
 - May not be able to get everyone to rally around one issue, but the Hill event was broad enough to have a value to each member.
- Discussion of common goals at a later meeting
 - We may need to put a sharper focus on goals
- Communication
 - Many issues are going directly to Barbara at NCBDDD
 - A second avenue is to use Jeremy Scott as a resource
 - Listserv is very useful
 - Website is also a good tool to update on EPG activities
 - Good highlight of each member in EPG and contact information.
 - Possible place where EPG members could get CDC press releases?
- How can we better serve you as a Partner to better the EPG, as well as individual organizations and the NCBDDD.

Future Activities & Events

- More Hill events
- Developing sub-committees
 - Newborn screening
 - Folic acid
 - State activities
 - Disabilities and health
 - Environmental health and tracking
- Publicize individual expertise by organization
- Creating a calendar of events and observances to help identify places where collaboration can take place.

***Next Steps**

- Next conference call may be sometime in August.
- Will develop a plan for the coming year and will distribute through the listserv.
- Please contact Jeremy Scott to be added to the Partners website, for any problems or questions after conference calls, and for questions about the directions and/or suggestions about future directions for the Partners Group.